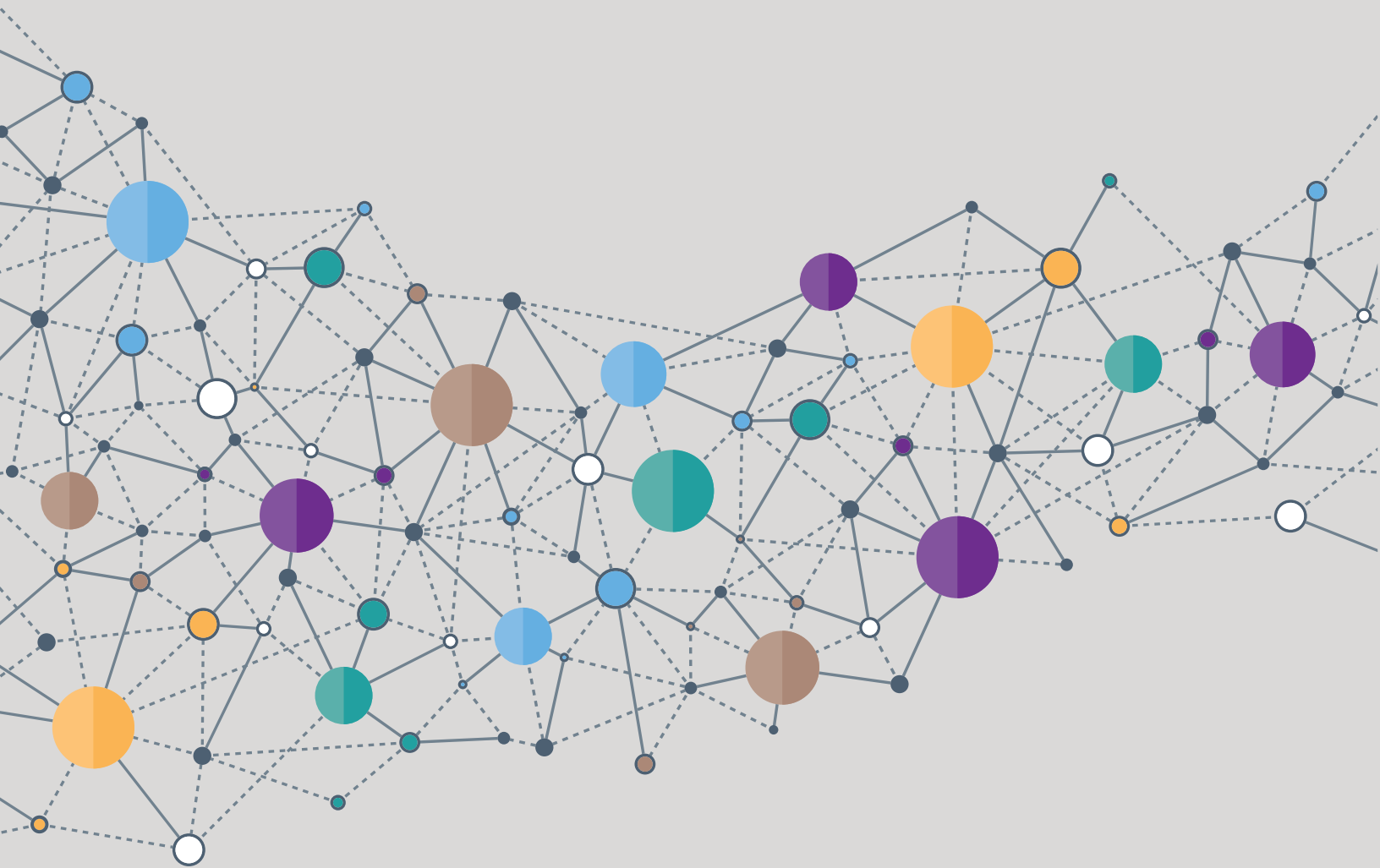


INNOVATE Research

Youth Engagement Guidebook for Researchers



Karleigh Darnay, MSW
Lisa D. Hawke, PhD
Gloria Chaim, MSW
Joanna L. Henderson, PhD
And the INNOVATE Research Team

camh | The Margaret and Wallace McCain Centre
for Child, Youth & Family Mental Health

INNOVATE Research: Youth Engagement Guidebook for Researchers

Printed in Canada

Copyright © 2019 Centre for Addiction and Mental Health

This guidebook may be freely reproduced for personal use. Other than for personal use, no part of this work may be reproduced or transmitted in any form or by any means electronic or mechanical, including photocopying and recording, or by any information storage and retrieval system without written permission from the publisher – except for a brief quotation (not to exceed 200 words) in a review or professional work.

Suggested citation:

Darnay, K.¹, Hawke, L.D.^{1,2} Chaim, G.^{1,2}, Henderson, J.^{1,2,3} and the INNOVATE Research Team (2019). *INNOVATE Research: Youth Engagement Guidebook for Researchers*. Toronto, ON: Centre for Addiction and Mental Health.

¹Margaret and Wallace McCain Centre for Child, Youth and Family Mental Health, Centre for Addiction and Mental Health

²University of Toronto

³Frayme

For more information, contact:

Lisa D. Hawke, Ph.D.

Centre for Addiction and Mental Health

1-416-535-8501 x39026

1 (800) 463-2338 x39026

Lisa.Hawke@camh.ca

Contents

Acknowledgements	4
Introduction.....	5
Part 1: Understanding youth engagement in research.....	7
Why engage youth in research?	8
The McCain Model of Youth Engagement	9
Types of youth participation	11
General principles of youth engagement	12
Dos and don'ts of youth engagement	13
Special considerations	14
Part 2: Planning for engagement in your project.....	15
Roles for youth in research	16
Positions for youth on your team.....	19
Considerations for your budget	22
Part 3: Finding youth for your team	23
Finding youth to join your team	24
Part 4: Working with youth on your team	27
Setting the stage for youth engagement	28
Bringing youth onto your project	30
Working with youth on your project	33
Challenges and possible solutions.....	36
Part 5: Evaluating and reporting on engagement	39
Evaluating youth engagement.....	40
Reporting on youth engagement.....	41
Part 6: Examples of youth-engaged research projects	43
Youth roles and research methodologies.....	44
Project summary: YouthCan IMPACT.....	46
Project summary: Web-based drug education resource	49
Project summary: Scoping review of youth friendliness	52
Part 7: Youth engagement planning worksheets	53
Your research project.....	54
Readiness to engage youth	55
Setting the stage for youth engagement	57
Supporting youth	58
Creating youth roles	59
Finding youth to join your team	60
Budgeting for youth engagement.....	61
Learning plan	65
Challenges and possible solutions.....	67
Tracking youth contributions	68
Part 8: References and resources.....	69

Acknowledgements

The following people have also contributed to the INNOVATE Research project:

Lisa Lachance^{1,2}, MPA, PhD Candidate
Skye Barbic^{3,4}, PhD, OT
Sophie Soklaridis^{5,6}, PhD
Sean Kidd^{5,6}, PhD
Tanya Halsall^{7,8}, PhD
Emma McCann⁵
Brandon Mott¹, BMus
Jacqueline Relihan⁵
Mo Khaleghi⁴

Steve Mathias^{3,4}, MD
Ian Manion^{7,8,9}, PhD
Srividya Iyer^{8,10,11,12}, PhD
Michael Ungar^{1,2}, PhD
Marion Brown², PhD
Shelly Ben-David^{3,4}, PhD, RSW
Csilla Kalocsai⁵, PhD
Renira Narrandes⁵, MA, MPH

¹Wisdom2Action

²Dalhousie University

³University of British Columbia

⁴Foundry

⁵Centre for Addiction and Mental Health

⁶University of Toronto

⁷University of Ottawa

⁸Frayme

⁹The Royal Ottawa Mental Health Centre

¹⁰McGill University

¹¹ACCESS Open Minds

¹²Douglas Hospital Research Centre

This project was supported by the Social Science and Humanities Research Council of Canada.



Social Sciences and Humanities
Research Council of Canada

Conseil de recherches en
sciences humaines du Canada



Introduction

About this guidebook

This guide was a collaborative project between the Margaret and Wallace McCain Centre for Child, Youth & Family Mental Health at the Centre for Addiction and Mental Health (CAMH) in Toronto, Wisdom2Action in Halifax, Foundry youth centres in British Columbia, Frayme, Dalhousie University, University of British Columbia, and McGill University. It has brought together teams who engage youth in research as a key tenet to operations and evaluation. As a team of researchers, staff who support youth engagement, and youth who work regularly as part of research teams, we share our experience in youth engagement through all stages of research projects to optimize research success and impact.

Who is this guidebook for?

This guidebook was designed for researchers across disciplines, who are interested in learning more about engaging youth in research.

What will you learn in this guidebook?

- What youth engagement in research looks like
- How youth can contribute to research
- How to build strong partnerships for successful engagement
- How to budget for youth engagement expenses
- How to find youth for your project
- How to work effectively with youth on your team
- How to evaluate engagement in your project
- Our experiences and project examples



PART 1

Understanding youth engagement in research

Why engage youth in research?

It is becoming increasingly important to engage youth in research being conducted about them. In the past, youth have typically been involved in research processes as participants. Youth engagement practices call for youth to be involved in more collaborative ways, to inform projects addressing youth-relevant issues.

Engaging young people in research has multiple positive impacts on the research project. When young people with lived experience of the issue being studied are engaged in research, this can result in:



- Research questions that are more relevant to the current youth experience
- Study designs that set you up for success
- Recruitment strategies that better reach your target population
- More youth-friendly recruitment materials



- Increased number of contacts with potential participants
- Increased study enrollment
- Better study retention



- Increased stakeholder buy-in
- Demonstration to your institutions and funders that you are researching real-world problems and real-world solutions
- Compliance with increased funder and publisher expectations for stakeholder engagement



- More relevant outcomes
- More effective knowledge translation to get your findings to people who will benefit from them
- Increased youth-friendliness of interventions



- Empower youth to become involved in science and community change
- Help engaged youth develop skills, self-efficacy, and social trust
- Build social engagement and long-term community citizenship among youth



We define “youth” as young people between the ages of 15-29 and refer to the practices in this guidebook as “youth engagement.” The age range may vary based on the project. These practices may sometimes be referred to as patient-oriented research, community engagement, participatory research and other terms.

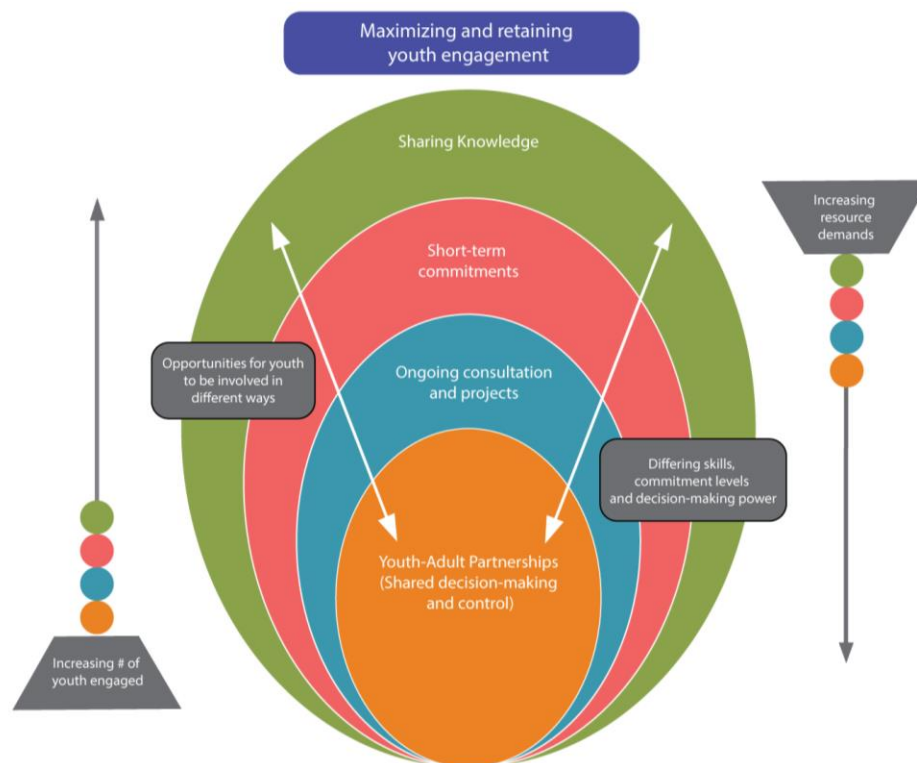
O'Mara-Eves, A., Brunton, G., Oliver, S., Kavanagh, J., Jamal, F., & Thomas, J. (2015). The effectiveness of community engagement in public health interventions for disadvantaged groups: a meta-analysis. *BMC Public Health*, 15(1), 129.

Domecq, J. P., Prutsky, G., Elraiyah, T., Wang, Z., Nabhan, M., Shippee, N., ... & Erwin, P. (2014). Patient engagement in research: a systematic review. *BMC Health Services Research*, 14(1), 89.

The McCain Model of Youth Engagement

The McCain Centre at the Centre for Addiction and Mental Health has developed an evidence-informed youth engagement strategy to inform and enhance research and other initiatives. The model supports McCain Centre and external research, provides a vehicle for ongoing service improvement projects, and increases collaboration, all while providing opportunities for youth skill development and empowerment.

The McCain Centre's Youth Engagement Model exemplifies a framework for understanding and promoting various pathways to engagement. The fundamental components of the model are choice, flexibility and opportunity. The model has the flexibility to match a broad spectrum of project needs with wide-ranging youth interests and skills and provides the opportunity for youth to be involved as much or as little as they wish.



Adapted from Carlson (2006). The Hampton Experience as a New Model for Youth Civic Engagement, *Journal of Community Practice*, 14:1-2, 89-106

Heffernan, O. S., Herzog, T. M., Schiralli, J. E., Hawke, L. D., Chaim, G., & Henderson, J. L. Implementation of a youth-adult partnership model in youth mental health systems research: Challenges and successes. *Health Expectations*, 20(6), 1183-1188. © 2017 Health Expectations
<https://onlinelibrary.wiley.com/doi/full/10.1111/hex.12554>; <https://creativecommons.org/licenses/by/4.0/>

For more about the McCain Model of Youth Engagement, see this youth co-authored publication by our team:



Heffernan, O. S., Herzog, T. M., Schiralli, J. E., Hawke, L. D., Chaim, G., & Henderson, J. L. Implementation of a youth-adult partnership model in youth mental health systems research: Challenges and successes. *Health Expectations*, 20(6), 1183-1188. © 2017 Health Expectations
<https://onlinelibrary.wiley.com/doi/full/10.1111/hex.12554>; <https://creativecommons.org/licenses/by/4.0/>

Types of youth participation

Participation

Young people are involved as research participants or are subjects of a research project. Examples of participation may include:

- Completing a survey
- Taking part in interviews or focus groups
- Participating in a clinical trial

Consultation

Young people act as an advisor and provide their feedback on a particular research project. Researchers take this feedback to a decision-making table to decide how this may influence their project. Examples of consultation may include:

- Joining an advisory group
- Providing feedback on project materials
- Participating in a forum on the research project

Partnership

Young people are equal partners with researchers. They are actively involved in collaborating on and leading research project activities. Examples of partnership may include:

- Sitting on a project steering committee
- Contributing to decision-making on research priorities and project methodology
- Supporting or leading project activities (focus groups, data analysis, manuscript writing, etc.)

Youth-led

Young people are leading the entire research project themselves or with the support of experienced researchers. Examples of youth-led activities may include:

- Applying for project funding and research ethics approval
- Identifying and training project staff
- Conducting all research activities from initiation to completion



Different types of participation may be better suited for certain projects. See pgs. 44-45 for research projects with different examples of engagement. See pgs. 16-18 for examples of different research activities youth may participate in.

Adapted from: Faithfull, S., Brophy, L., Pennell, K., & Simmons, M. (2018). Barriers and enablers to meaningful youth participation in mental health research: Qualitative interviews with youth mental health researchers. *Journal of Mental Health*, 28(1), 56-63, doi: 10.1080/09638237.2018.1521926.
CMHDARN, Ask the Experts: A CMHDARN Best Practice Guide to Enabling Consumer and Carer Leadership in Research and Evaluation, Sydney, 2015.

General principles of youth engagement

Supporting partnerships between youth and researchers

Strong partnerships are key to successful engagement. Important components of partnerships between youth and other researcher team members include:

- **Flexibility:** Developing roles that can be changed based on young peoples' skills. Being flexible around deadlines and overall goals when possible.
- **Mentorship:** Providing the mentorship and support to help youth engage effectively in the research process.
- **Mutual respect:** Avoiding power imbalances between youth and other project team members. Creating a welcoming environment where all opinions and contributions are valued.
- **Authentic decision making:** Recognizing young people as partners in decision making rather than consumers or consultants.
- **Reciprocal learning:** Understanding that all parties are both teachers and learners. Through a co-creation model, a team with diverse expertise can work together to create a more successful, well-grounded, innovative research project.

Dos and don'ts of youth engagement

For a review of practical tips for youth engagement, see the following youth co-authored publication. Key points are summarized below.



Hawke, L.D., Relihan, J., Miller, J., McCann, E., Rong, J., Darnay, K., . . . Henderson, J.L. (2018). Engaging youth in research planning, design and execution: Practical recommendations for researchers. *Health Expectations*, 21(6), 944-949. © 2018 Health Expectations
<https://onlinelibrary.wiley.com/doi/full/10.1111/hex.12795>; <https://creativecommons.org/licenses/by/4.0/>

 Do...	 Don't...
Have clear expectations Know your goals and objectives and share them with your youth partners; be clear about the youth's role and contribution.	Dominate the conversation Youth can feel intimidated or uneasy participating in meetings or projects that don't make space for their participation.
Be partners Integrate youth voice into decision-making and identify environmental barriers to engagement.	Be tokenistic Ensure that youth voices are heard and acted upon; value youth perspectives and representation as stakeholders in your work.
Check in Act as an adult ally by listening to youth feedback and offer mentorship where appropriate.	Privilege one form of knowledge The purpose of collaboration and consultation is to have a diversity of voices at the table.
Give time Allow time for reflection; pre-brief and debrief sessions can clarify and build confidence.	Disregard feedback Make space in the project timeline for consideration of feedback and follow up on the outcomes
Recognize diversity No single youth represents all youth perspectives; diverse voices deserve to be heard, respected and considered.	Steer youth Allow youth to guide the conversation towards the issues and ideas that are most important to them.
Value contributions Compensate youth for their participation in projects by providing a wage or honorarium.	

Special considerations

This guidebook lays out a general framework for youth engagement in research. Remember that all youth are unique and working with youth on your team may look differently. There are multiple intersectionalities that can influence engagement with young people in research. This includes working with LGBTQ+, newcomer or First Nations, Inuit and Métis youth, youth with disabilities, youth experiencing homelessness and many more.

No matter where your target group of youth comes from, think about what practices or adaptations will best support youth on your team. Here are some considerations you may take and apply to the specific population of youth you will be working with:

- Engage members from these communities on your team for guidance and support (should include both research and non-research members).
- Partner with researchers who have experience working with the specific youth population you are targeting.
- Offer trainings for your team on best practices when working with specific populations.
- Consider specific supports youth may need to be actively involved on your team.
 - Do youth on your team need any physical accommodations?
 - Would youth appreciate more support to participate in project meetings or complete activities?
- Consider taking a trauma-informed approach. Be sensitive to the different life experiences youth may be bringing to the team and what supports youth may need when discussing sensitive topics.
- Follow specific ethical review procedures, and adhere to the ethical principles of research within these communities if they exist (e.g., TCPS 2 – Research Involving the First Nations, Inuit and Métis Peoples of Canada).



As you read and work through this guidebook, think about the population that you will be working with and any additional adaptations that may be helpful. Once youth are engaged on your team, ask youth themselves for support in this area, too!



PART 2

Planning for engagement in your project

Roles for youth in research

Project planning

<i>Developing the research question and objectives</i>	• Working with the planning team on an ongoing basis to identify and co-develop research questions • Ensuring the research question is relevant to the youth experience • Providing recommendations on study outcomes to align with real world experiences and that are important to youth • Selecting project values and goals to guide the project
<i>Guiding research methods used</i>	• Advising on literature review search terms • Supporting options for intervention design and delivery • Advising on the recruitment strategies ○ Providing feedback on or creating recruitment posters and scripts • Supporting the development of study materials with youth-friendly language ○ Project overview or FAQ page for participants ○ Consent forms ○ Surveys ○ Interview or focus group questions • Identifying any barriers to participation and mitigating strategies ○ Eligibility criteria ○ Methods of data collection (e.g., location, time, etc.) ○ Compensation • Discussing appropriate study measures with the research team • Optimizing the role of technology in the project • Suggesting areas for further youth engagement



Remember that youth are experts in their own experience—they know what they want, they know what they would use, and they know how they would use it. This applies not only to aspects of the question the research is exploring, but also to aspects of conducting the research project itself, such as what would need to be in place for youth like them to choose to participate in the project.

Project activities

<i>Supporting recruitment strategies</i>	• Advising on how and where to reach participants ○ How to make the study attractive to participants ○ Recruiting online, in-person, in specific locations • Forwarding study flyers through their networks and connections • Supporting participant onboarding
<i>Supporting data collection</i>	• Facilitating or co-facilitating interviews or focus groups • Training research assistants on youth-friendly ways of working with potential youth participants • Providing suggestions to optimize retention

Data analysis and interpretation

<i>Supporting data-analysis</i>	• Identifying questions for data analysts to explore • Actively analyzing or co-analyzing study data, depending on the study data and the skills and interests of the youth
<i>Interpreting study findings</i>	• Discussing study findings with the researchers to help interpret findings through a youth lens • Providing insight into any of the results or limitations of the study • Reviewing outcomes to generate new project ideas



If the youth you engage will have direct contact with study participants or will have access to study data, consider how to write this into your Research Ethics Board applications and ensure that the youth have all of the appropriate research training (e.g., TCPS 2).

Knowledge translation

<i>Supporting manuscript development</i>	• Meeting with researchers to discuss content and provide feedback • Writing or reviewing manuscripts • Being a co-author or acknowledged member
<i>Reaching the intended population</i>	• Developing resources • Presenting findings through social media, at community events, etc.
<i>Sharing knowledge with key stakeholder groups</i>	• Co-presenting study findings at conferences • Developing blog posts, podcasts, etc. • Co-hosting webinars and workshops on all aspects of the project they were involved in including project methods, youth involvement, study findings, etc.



When considering co-authoring publications with youth or acknowledging their contributions on a manuscript, it is important to discuss the implications with them prior to doing so. Do they want their role to be acknowledged in a permanent way? Despite the researchers' wish to acknowledge the youth personally, the youth may wish to remain anonymous. Open and honest discussion prior to inform decision making is key.

Positions for youth on your team

The contributions that youth can make on a project depend in part on the role they play as part of your team. Consider the skill sets and level of commitment that align best with your project's needs.

More intensive engagement

Youth in these roles are project team members and equal partners in project activities. They may attend regular project meetings with the researchers, support the development of project materials, and facilitate the engagement of broader groups of youth.

Youth Staff

- May be appropriate for projects that are longer in duration and have funding for a youth position.
- Youth have consistent project responsibilities that require a regular schedule, substantial time commitment, and heightened level of independence.
- Youth in these roles may support multiple research projects on related topics.
- Youth in these roles may also liaise with a broader group of youth who are less intensively involved (see next page).

Youth Advisors

- May be appropriate for projects that are shorter in duration or have limited resources for a youth position.
- Youth maintain a more flexible schedule and can be paid through honoraria.
- Youth may attend project meetings that are held less frequently.
- Youth may have a lower level of commitment over a longer period of time or a higher level of commitment over a shorter period of time.



Consider engaging multiple youth in more intensive positions. Having peers may support their participation, bring diverse skills and perspectives to your project and can also help with flexibility if any challenges arise.

Less intensive engagement

A project may benefit from less intensive engagement of a larger number of youth. This type of engagement can make it possible to access a more diverse set of youth voices, with engagement activities being less intensive for both the youth and the research team.

Youth Advisory Group Members

- Youth commit to attend regular advisory group meetings throughout the project.
- Youth are provided with an honorarium for each meeting.
- Youth attend meetings, and may also have opportunities to participate in additional roles outside of project meetings.

Youth Consultations

- One-time consultations with a broader group of youth.
- Youth with different levels of experience and skillsets can participate.
- Requires a low level of commitment from youth and project staff.
- Youth receive a one-time honorarium for the consultation.

Youth partners with the skill set you need

The skill set needed will depend on the level of engagement best suited to the project activities and the support that the research team can provide. Consider some of the following areas of youth skills, knowledge, and abilities that may support and enhance your project. Since different youth will bring different skill sets to the project, you might consider bringing multiple youth on your team to provide diversity.

- Knowledge or lived experience in project topic area
- Ability to provide knowledge from own experience and speak from a broader youth perspective
- A passion for working in the project topic area
- Ability to commit to a regular schedule, attend regular meetings, and respond to emails in a timely manner
- Critical thinking skills
- Capacity to work independently and also with the support of research staff as needed
- Group facilitation skills (e.g., if co-facilitating advisory group meetings or focus groups)
- Public speaking and communication skills
- Commitment to youth-friendliness (e.g., ability to connect with other youth, an understanding of youth-friendly language, etc.)
- Multimedia and/or graphic design skills to develop youth-friendly project materials
- Strong existing connections with relevant youth-focused organizations
- Relevant training and/or research experience



Think about the skills youth should already have when joining a project, as well as the skills that they may be able to develop as they gain experience on the project.

Considerations for your budget

Writing youth engagement into grant applications

You can develop a budget based on your youth engagement plan. When well justified, funding agencies are often ready and willing to support engagement. Consider writing youth engagement directly into your grant applications to ensure that you have the funds you need to apply the practices you have selected for the project.

Possible budget lines & justification:

- Consistent with the McCain Model of Youth Engagement and supporting effective youth-adult partnerships (Heffernan et al. 2017), we will require the services of a Youth Engagement Coordinator to work with the youth to ensure appropriate, informed, productive engagement that benefits both the youth and the research team (\$XX/h + 25% benefits x 200h/year = \$XXXX).
- Throughout the study, two youth advisors will be members of the research team (200 h / year x 2 youth; \$XX/h + 25% benefits, per standard institutional rates = \$XXXX per year). They will support the team in developing and conducting youth-friendly study processes and co-developing the youth-friendly reports, with the ongoing support of the research team.
- We will conduct youth advisory group meetings every six months throughout the duration of the project. Youth will receive a \$50 honorarium for each 2 hour consultation, as per standard institutional rates. At six advisory groups per year, with 8 youth each on average, at \$50 per youth, we request a budget of \$XXXX per year to support strong youth engagement practices. This will enable us to benefit from a diverse range of youth voices to inform the project.
- To support youth attendance at meetings, we will require funds to reimburse youth for transportation (\$3 x 2 public transit fares x 8 youth x 6 meetings), as well as snacks and materials such as printing and fidget toys to maintain engagement during meetings. At \$XXX per meeting and six meetings per year, we request \$XXX per year for the duration of the project.
- Youth will be consulted periodically to support the project. We plan for three individual consultations of two youth per year. Youth will receive a \$XX honorarium for each 2 hour consultation, as per standard institutional rates. At three consultations per year, with 2 youth, at \$XX per youth, we request a budget of \$XXXX per year. These will include project planning consultations and participation in knowledge translation activities.



PART 3

Finding youth for your team

Finding youth to join your team

Youth staff & advisors

- You may need to work with your institutional Human Resources department to create a new position title/category, job description, job posting and interview process.
- The job posting should be as clear as possible.
- Screen cover letters and resumes to ensure the interviewees are young people with the skills and experiences needed.
- Develop an interview that gauges their experience and skill set, while also asking them what skills and experiences they would like to develop.
- Whether a formal interview or an informal meeting, it is important to provide an opportunity to meet individually with interested youth to provide information about the role and determine together if their experiences, skills, abilities, and interests are a match for the roles and the level of engagement required.

Youth advisory groups & consultants

- Recruit youth using a project flyer and distribute broadly in places where youth in your target population may be located in the community.
- Aim to recruit a mixed group of youth within your target population who have the various levels of experience, skill sets, and abilities that will complement your project team.
- If youth will be engaged in regular advisory meetings, plan an introductory meeting to provide youth with more information about the role and to determine if their experiences, skills, abilities and interests are a match for the role and the level of engagement required.
- Consider holding a group orientation session where you can describe the project and roles, giving youth the opportunity to consider whether advisory group membership is a good fit for them.

Tips for creating effective youth postings

Whether you are recruiting through a poster or a job posting, try to ensure that the information attracts youth with the experience and skill set you are looking for. Creativity may be required.

- Provide information about time commitment for the project.
- List required skills and responsibilities.
- Try not to provide too much information on the posting. More details can be given during an introductory meeting.
- Try to make the recruitment materials fun, engaging, and youth-friendly. Avoid jargon that may not be easily understood by youth. You may consider sharing draft versions with young people for feedback.
- Consider sharing your postings with partners who are already working with young people in your target population. They may be able to refer youth to your team.

Sample youth postings

INTEGRATED SERVICE HUBS FOR YOUTH MENTAL HEALTH AND/OR ADDICTIONS

As a team of researchers at CAMH, we are developing a survey to be launched in the next year across Ontario, to better understand youth, caregivers and service providers service preference for Integrated Service Hubs (like a one-stop-shop for youth mental health and/or addictions services).

We are looking for a youth advisor to join our planning team to make sure this new content has the greatest impact! As part of our team you would be attending meetings on the 3rd Tuesday of each month from 11AM-12PM, with additional time on the project for check-ins or project planning as needed. Additional time would be based on your availability.

As a member of the project you would be able to:

- Provide suggestions on the content of the survey
- Assist with planning of the youth focus groups
- Assist with running the youth focus groups as a co-facilitator with the support of the project team

This would involve a 6 month commitment, with the p extension.

If you are interested, please email _____

WORK TOGETHER WITH YOUTH FROM ACROSS ONTARIO TO

DEVELOP A DRUG EDUCATION RESOURCE

Are you interested in helping create
a digital resource about
SAFER DRUG USE?

Are you between the ages of 17 and 24?

Share your insights about drug use and drug education.

Contribute your ideas to the design of safe drug use
education in a full day workshop.

Lunch and honorarium provided.





PART 4

Working with youth on your team

Setting the stage for youth engagement

Training research staff

If youth engagement is new to your research team, it is important to orient team members to the process. When team members are aware of the value and impacts of youth engagement, they may be more ready to engage in the process. If there are any youth engagement trainings available in your area, you might encourage team members to attend. If you and your team are new to youth engagement, consider who you can connect with for mentorship. Other opportunities include:

- Sharing this workbook with them
- Working through the worksheets with them
- Distributing and discussing documents in the resource section of this workbook
- Having a team meeting dedicated to youth engagement to encourage open and honest discussion about team members' thoughts, concerns, and notions of engagement
- Bringing youth to team meetings to introduce them and discuss their role (once youth are engaged)
- Holding debrief sessions with the research team once you've begun youth engagement to address their concerns and their positive experiences
- Continuing ongoing open discussion about the successes and challenges of youth engagement

Support from project allies

To engage successfully in research, youth need the support of a project ally. This team member is the key contact for the youth and bridges the gap between the researchers and the youth. Whether the person supporting young people on your project is someone already working on your team or you are hiring a new staff member, here are some considerations to ensure the project ally is well suited for this role.

Experience

- If possible, it's important for staff in a project ally role to have previous experience working directly with young people and also in research.
- If engaging youth in research is new to the project ally, they should receive training.

Youth-friendliness

- The project ally should be able to support young people in contributing to a project. They can be advocates for the young people, helping to ensure that youth can participate in meaningful ways.
- They should be open and welcoming so young people feel comfortable working alongside them.
- They should have the ability to translate research terminology into youth-friendly language.
- They should think actively about the ways that spaces can feel more inviting to young people.
- They should be able to focus on engaging youth in the specific project at hand while maintaining an awareness of the youth's learning goals to support them in moving forward upon project completion.

Selecting a project ally

- Whether hiring a new staff member or selecting a project ally from among your existing staff, consider conducting an interview to understand how the person has worked with young people in the past and how they would support young people's engagement.
- If possible, have young people participate in the selection process to help select someone they will be comfortable working with.

Bringing youth onto your project

Now that you have found youth to work on your team, consider how to bring them onto the project. The project ally you've identified should be involved in this process.

- First, consider holding an introductory meeting with the youth to describe the project. Talk about what the youth role may look like and answer their questions. See the guideline on the next page to help with this conversation. You might hold the meeting in an informal space to facilitate team building.
- Is there any training that the youth can participate in to support their role on the project? You might consider training on topics such as the following:
 - Your research topic
 - Your project objectives and milestones
 - Your team's structure and decision-making process
 - Research ethics (TCPS 2)
 - Standard organizational training
 - Public speaking and group facilitation skills
 - The benefits and challenges of sharing their story
- Consider whether you might have project summaries or project protocols that they can review. Would it be helpful to produce a youth-friendly version of protocols?
- Consider developing a learning plan that incorporates the skills they are already bringing to the project and the skills they want to develop. These plans can be a point of discussion throughout the project. They will provide information on which project activities may be more appropriate for which youth and may highlight any training needs.
- Are there any activities that you can plan to support relationship building on your team as a whole or among youth members themselves? It is important for youth to feel connected to the work they are doing and also comfortable with the project team. Consider a small activity during project meetings or an informal retreat.

Developing structured processes to support engagement

Use the following pages to guide an onboarding process for youth members onto your project. Consider which pieces can be covered in an orientation or terms of reference document, as well as areas that you may co-develop with youth on your team.

About the project	• Provide a summary of the research project • What is the research question and goals for the project? • Are there any project values that have been chosen by the team? • Who will be the point of contact and support (project ally) for youth on the project? • Who are the project team members and other partners that youth may meet through project meetings?
Youth membership	• Who are the youth members on the project? ○ Do you have youth partners who attend project meetings? ○ Do you have a youth advisory group? • What experience are they bringing to the project? • Do they represent a specific age range or population?
Roles	• What are the roles for youth on the project? • Are there different roles or levels of commitment expected for different members? • What activities will they participate in?
Meetings	• Will there be regular meetings that youth will attend? ○ Project committee meetings, youth advisory meetings, etc. • What is the meeting frequency and when do meetings occur? ○ A set day each month, selected by a poll, etc. • How do these meetings occur? ○ In-person, teleconference, video conference etc.
Compensation	• How will youth members be compensated? ○ Monetary: cheque, electronic transfer, cash, gift card ○ Volunteer hours, reference letter • When will payments be issued? ○ After each meeting? Once every two months? • How will hours on the project be tracked and who will track them?

Accountability	• Who is the youth accountable to? • What are the responsibilities of youth team members? ○ Attend as many project meetings as possible. You might consider establishing a minimum number of meetings the youth must attend to remain an active member of the team. ○ Notify a contact person if unable to attend or if their availability changes ○ Respond to communications in a timely manner ○ Follow project timelines when applicable • What are the responsibilities of the research team? ○ How will recommendations from youth members be considered? ○ How will decisions be made and shared back with youth members? • Will there be group guidelines to follow or project values to uphold?
Confidentiality	• What commitment will team members make to maintaining confidentiality? ○ Any identifying information will not be shared. ○ Project information will not be shared until it is released to the general public. ○ Outline the limits of confidentiality. • Will members sign a confidentiality agreement?
Safety	• Could any project discussions be potentially triggering for youth? How will you negotiate this with team members and provide support if needed? Clarity around the point person or project ally and support protocols will help ensure safety. • It may be helpful to provide emergency resources for youth members or develop safety protocols if applicable.



It may not be appropriate for youth team members to have complete anonymity on the project. For example, co-authorship may identify them as youth with lived experience of the topic. Discuss anonymity versus public credit with the youth early so they can decide what information they agree to make publically available about their role.

Working with youth on your project

Supporting regular project meetings

When having youth team members at research meetings, be prepared to do things a bit differently. The point person or project ally you've designated to work with youth should be involved at this stage. This person can also be helpful in planning for project meetings and supporting youth during meetings.

Working with youth as part of broader project meetings

- Hold pre-brief meetings to review the agenda and materials with youth.
 - Youth can ask questions, identify points they would like to provide feedback on, or suggest additions to the agenda.
 - You can explain items on the agenda that may not be easily understood, such as acronyms and terminology, as well as background information leading to the discussions at hand.
 - You may suggest several possible directions that the discussion might take, to help youth follow the discussion in the main meeting.
 - Youth can use the meeting to discuss and prepare information or feedback they would like to share in the meeting.
- During meetings, the project ally can ensure that young people have the opportunity to participate.
 - The project ally can help ensure that the language being used is understandable.
 - The project ally can help youth share their comments in the meeting by creating an opening for them in the conversation and supporting open dialogue where both the youth's and the researchers' voices are heard.
 - The project ally can also work with the full project team, including the youth, to decide if any items should be taken to a larger group of youth for broader consultation, e.g., youth advisory group.
- De-brief with youth after meetings to review how the meeting went.
 - What went well or can be improved for future meetings?
 - Is there anything that youth did not understand that you can clarify?
 - Are there any areas where youth wanted to give feedback but did not? Did they feel heard? What changes can be made to help them contribute to meetings in the future?

Scheduling regular project meetings or youth advisory meetings

- Be flexible when planning meeting times. Youth may have school or other commitments. Sometimes meetings during a typical 9am-5pm day will not work best for youth.
 - Are your meeting times flexible or will you have meetings at a set date/time each month?
 - If flexible meeting times are not feasible, this should be discussed at the hiring and selection stage.
 - Consider using a poll such as Doodle Poll to select meeting times with your team and to ensure the largest number of youth members can attend.
 - Depending on your project and a youth's comfort level, is it possible to attend meetings over the phone versus in-person? If holding meetings over the phone, consider using video conferencing.
 - Consider alternatives to email for collaborating on project materials, such as Slack or Google Drive.
 - Try to make your meetings more informal and engaging. Depending on the type and frequency of the meeting, you might provide a time for introductions, icebreakers, and other youth-friendly adaptations or activities.

Planning for youth advisory meetings

Here are some tips that members of our team find helpful when running advisory group meetings.

Preparing for the meeting

- Send out reminders the day before or on the day of meetings, depending on the preference of your advisory group members.
- Host the meeting at an accessible time and location.
- Create a youth-friendly space:
 - Include snacks, fidgets, sticky notes, flip chart paper, colouring sheets, etc.
- Prepare a youth-friendly meeting agenda and materials.
 - Consider creating a facilitator agenda and a summarized version for youth.
- Consider an informal look, e.g., dressing more casually and removing staff badges

Hosting the meeting

- Start the meeting with introductions: name, pronouns, and an icebreaker.
- If this is your first meeting:
 - Consider allocating time for members to get to know each other.. What are their hopes for participating in meetings? Do they have any hesitations?
 - Develop or review the terms of reference for the advisory group with members.
 - Lead an activity to establish group norms and guidelines for creating a safer space.
- Review the meeting agenda and leave time for questions.
- Consider having youth feedback as a standing item on the agenda.
- Plan for a break during the meeting, time at the end of the meeting to discuss next steps, and time after to provide honorarium, public transit fares, etc.
- Create opportunities for youth to participate in different ways.
 - For example, some members may be more comfortable writing down their ideas instead of sharing out loud or participating in group activities.
- It may be helpful to organize an activity at the end of the meeting to check in with the youth, especially if the meeting topic is more sensitive.

After the meeting

- Debrief with the youth facilitators or other youth, as needed.
- Send meeting notes to members, noting any action items in particular, and follow up with anyone who was not able to attend. You might consider asking for their feedback on agenda items online.
- Discuss the results with your research team and plan for next steps.
 - Consider how you will use the youth feedback, how you will let them know how you are using their feedback, and how you will acknowledge their contribution. If you are not using their feedback, it is helpful to share the reasons with the group.
 - Keep track of the ways that youth have contributed to or steered the project for evaluation and reporting.

Challenges and possible solutions

Supporting meaningful youth engagement on research projects is not without its challenges. Here are some possible challenges, and their possible solutions.

Examples of challenges

CHALLENGE	POSSIBLE SOLUTION
1) Your team was not fully ready to engage youth on the team.	Check in regularly with project staff and youth partners throughout the project to understand how engagement is working. If needed, provide training for the team on the value of youth engagement and offer more direct support.
2) Your institution or broader research community does not appreciate the value of youth engagement.	Lead by example: clearly demonstrate and report on the value that youth engagement has brought to your team. You may also be able to find other champions within your organization or the research community to partner with or learn from.
3) The youth voices and experiences on your team are not sufficiently diverse.	Work with community partners to recruit diverse youth representative of the target population. Think about any barriers that present challenges for youth to engage in your project and try to address these barriers.
4) Youth turnover is high, creating barriers to project development.	Speak with youth team members for feedback on areas for improvement. Think about ways to improve the experience for young people on your team and the youth-friendliness of your communications, meetings, etc. Work with the youth to ensure that their engagement on the project helps them meet their own goals and that the compensation and recognition you are providing is meaningful to them.
5) Youth remain on your team so long that they become “junior researchers” and no longer represent youth voice.	Work with the youth to establish goals and timelines related to their participation in the project and support them in transitioning out of the role once the goals are achieved, moving on to their next goals.
6) Youth schedules are difficult to accommodate.	Be transparent about schedules when onboarding youth members and working with project staff. Plan for different levels of youth participation to accommodate different schedules. Work with your team to encourage flexibility in team members’ schedules.

Examples of challenges (cont'd)

CHALLENGE	POSSIBLE SOLUTION
7) Youth do not have the skills or readiness to participate as research partners.	Identify the skill set needed before recruiting youth and select accordingly. Work with youth to determine their project role-related learning needs and provide training and support as needed. If appropriate, see if youth are better suited for a lower level of engagement where they may be able to build their skills over time.
8) Sufficient funds are not available to support youth participation in the research.	Write youth engagement expenses into grants; seek donor support and other creative funding opportunities. If necessary, work with youth to identify non-financial ways of adequately acknowledging their contributions (e.g., volunteer hours, reference letters).
9) It is difficult to recruit youth.	Work with community partners or youth organizations to recruit and encourage partners to directly refer youth to your project. If you have any youth members on your team, work with them to strengthen your recruitment materials or onboarding process.
10) Youth do not engage, attend meetings, or produce deliverables.	Have a dialogue with the youth to understand their goals and concerns. Determine if they are interested in re-engaging and if so, provide support and appropriate learning opportunities. Engage multiple youth with different skill sets to produce required deliverables.
11) Tension or conflict among youth has emerged on your team as youth have different roles and recognition.	Describe the flexible nature of the roles and responsibilities for youth at the beginning of your project if applicable. Offer reminders that participation may look differently for different youth based on the experience or skillset they are bringing. Try to be transparent in decision-making if youth are given different roles and work with youth when possible to make this a joint process. Try to recognize all youth partners at different times and in different ways.



PART 5

Evaluating and reporting on engagement

Evaluating youth engagement

Evaluating the engagement process and the impact it has had on your project will provide valuable information about what worked well and what could be improved. It is important to outline a clear plan prior to beginning the engagement process. Evaluation can provide valuable feedback to the team and will be instructive for future projects. If your actual experience is different from the experience you foresaw, that doesn't mean it was a failure — it was just different. This process is a learning experience for everyone.

Evaluating the impact of engagement on your project

The researchers' perspective

- How valuable did the researchers consider the youth role on the project?
- What project phases or activities did youth participate in?
- To what extent were youth involved in key decision making on the project?
- To what extent did the team listen to and act on youth feedback and recommendations?
- How did youth engagement influence the project?
- What was the time and financial investment required to engage youth?
- What did engagement allow your team to do differently?
- What products or deliverables did youth stakeholders develop or co-develop?
- What presentations did youth participate in?

The youth perspective

- How valuable do youth find their role on the project?
- What project phases or activities did youth feel they were involved in?
- To what extent do youth feel that they have been involved in key decision making on the project?
- To what extent do youth think their feedback and recommendations were listened to and acted upon?
- How do youth feel they influenced the project?
- To what degree do youth feel there was there transparency in decision-making?
- Do youth feel they were provided with opportunities for growth and development?
- How do youth feel about the support they received from a project ally?
- Do youth feel that the project environment was youth friendly? (i.e., project meetings, work space, relationships with team members, etc.)



Consider using both qualitative and quantitative evaluation methods. Several useful evaluation resources for engagement can be found in the references and resources section on pg. 71.

Reporting on youth engagement

Youth engagement is not just something you do quietly in the background. More and more funders, accreditation bodies, and institutional leaders value youth engagement and expect youth-oriented, youth-engaged approaches. You can highlight the process and impact of your youth engagement work:

- In primary project peer-reviewed publications.
- In youth engagement-focused peer-reviewed publications In press releases about your project and subsequent media interviews conducted together with youth.
- In institutional and funder reports.
- In your promotion dossier, linking youth engagement to real-world research relevance.
- In local talks at your institution.
- At conferences, co-presenting with youth where feasible.
- In your “most significant contributions” section of grant applications.



When you experience the benefits of youth engagement — and the value it can bring to the research process — you may find yourself becoming an advocate as you INNOVATE Research in your area of shared expertise.



PART 6

Examples of youth-engaged research projects

Youth roles and research methodologies

Youth can be engaged in a wide variety of research designs and methodologies. Here are examples of projects that have incorporated youth engagement, the degree of engagement in each one, and how youth have contributed.

DESIGN	TOPIC	ROLE	EXAMPLE CONTRIBUTIONS
Consultation			
Scoping review *see project description on pg. 52	Youth-friendly mental health services	Consultants (3 youth)	• Advised on keyword identification and interpretation • 1 youth co-facilitated member checking focus group with the support of project researcher
Partnership			
Randomized-controlled trial *see project description on pgs. 46-48	Community-based integrated collaborative care team model (YouthCan IMPACT)	Project staff (1 youth) Advisory group (12 youth)	• Members of core project working groups • Collaborated on key outcome measures for the study • Identified project values • Co-developed service and research pathways • Reviewed and collaborated on participant recruitment and onboarding materials • Created multiple educational materials for study participants • Co-authored 2 publications • Co-facilitated 2 conference presentations
Co-production, informed by participatory research methodologies *see project description on pgs. 49-51	Co-production of a web-based drug education resource with and for transitional-aged youth	Project staff (1 youth) Project advisors (4 youth) Advisory group (6 youth) Focus groups (5 groups with 50 youth in total)	• Members of core project working group • Shared decision-making in project design and direction • Co-developed and co-facilitated focus groups and development/design-oriented discussion groups • Interpretation of study data • Collaboration on final resource content and platform design

Youth roles and research methodologies (cont'd)

DESIGN	TOPIC	ROLE	KEY CONTRIBUTIONS
<i>Partnership</i>			
Randomized-controlled trial	Tertiary prevention intervention for youth transitioning out of homelessness (HOP-C)	Project staff (3 youth peer support workers)	• Members of core project working groups • Shared decision-making in project planning • Service delivery for study participants • Co-supervision and provision of trainings to other PSWs • Co-authorship on presentations and publications
Open trial	Integrated care pathway for depression (CARIBOU)	Project staff (2 youth) Project advisor (1 youth)	• Members of core project group • Co-designed service delivery pathway, including psycho-ed presentations, CBT manual and educational materials • Co-developed focus groups • Co-facilitated psychoeducational group • Co-facilitated conference workshop
Discrete choice experiment	Integrated care for youth (Wish List)	Project staff (1 youth) Project advisors (3 youth)	• Members of core project group • Item selection and refinement • Co-development of focus groups
<i>Youth-led</i>			
National mixed-methods survey-focus group	System navigation tool development (Wellness Quest)	Project staff (1 youth) Project advisors (6 youth focus group leads, 3 youth manuscript writing)	• Project leads with support from 2 researchers, 1 project ally • Designed project methodology • Applied for grant and REB • Developed national survey and focus groups • Trained project advisors • Facilitated focus groups • Analysis and interpretation of data • Final tool development and distribution • Manuscript writing

Project summary: YouthCan IMPACT

The YouthCan IMPACT project was funded by OSSU (the Ontario SPOR [Strategy for Patient-Oriented Research] SUPPORT [Support for People and Patient-Oriented Research and Trials] Unit) in 2015 and the Canadian Institutes of Health Research in 2019.

The project is a community implementation project and pragmatic randomized-controlled trial comparing community-based, integrated youth mental health and addictions services to treatment as usual at local hospitals in the Toronto area. Through cross-sectoral collaborations, the Integrated Collaborative Care Team (ICCT) model provides stepped-care services with low-, mid- and high-intensity interventions for mental health and addiction disorders in co-located, community-based walk-in service hubs. It is taking place in five area hospitals and three community ICCT service locations. Highly collaborative in nature, the project brings together psychologists, psychiatrists, methodologists, nurses, social workers, community service managers, direct service providers, caregivers, and, of course, youth.

How have youth been engaged?

This is a researcher-initiated project with a model of shared decision-making with youth. Youth have been engaged from the early project development phase, including the initial grant development phase, through to the full implementation of the model in the community and the ongoing operation of the randomized controlled trial.

“Youth Engagement Facilitators” are young people on staff who are full members of the research team’s governance model. They participate as full members of the Core Team meetings, as well as meetings of the Community Working Group, Implementation Science Working Group, and Methods Working Group, providing feedback at all phases of the project. They are supported by a Youth Engagement Coordinator, who is a social worker by training and is their designated project ally.

In addition to the youth on staff, the project has a Youth Advisory Group that meets periodically to consult on questions of specific interest to the team. The Youth Advisory Group meetings are facilitated by the Youth Engagement Facilitators, who bring the feedback from the broader Youth Advisory Group back to the team meetings.

#YouthCanIMPACT

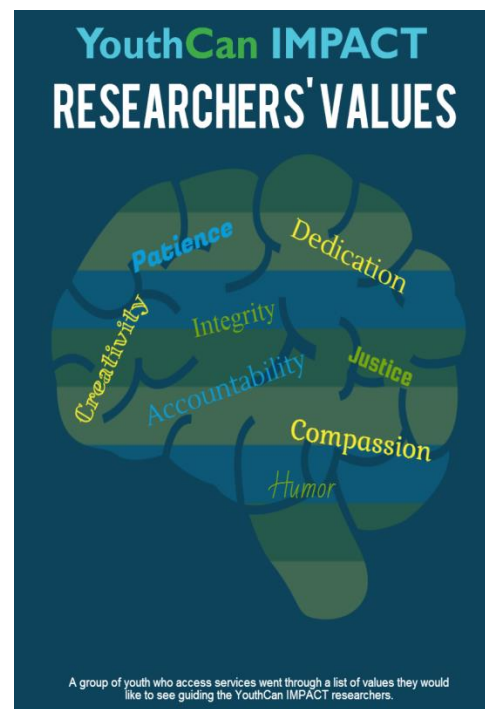
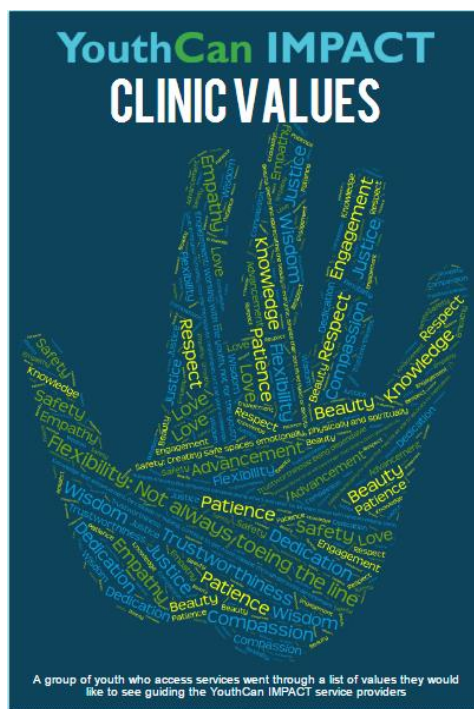
www.youthcanimpact.com

youthcan.impact@camh.ca

Key contributions:

- Selection of the primary outcome for the study (functioning), which was identified as being more important to youth than the initial researcher-identified outcome (symptom reduction)
- Identification of key values for the project, including value sets to guide both the clinical and research work
- Selection of mobile applications to integrate into the service delivery pathway and training of the direct service staff on these applications
- Co-design of the project website
- Development of youth-friendly participant recruitment and retention materials
- Development of youth-friendly materials for the clinical setting describing the services available
- Training of research assistants on how to engage effectively with youth research participants
- Co-authorship on publications
- Co-presentation of the project at local, national, and international conferences
- Co-facilitation of a webinar on the project:
 - <https://eenet.ca/resource/youthcan-impact-service-pathway-youth-mental-health-and-addiction-challenges>

Youth-developed project values



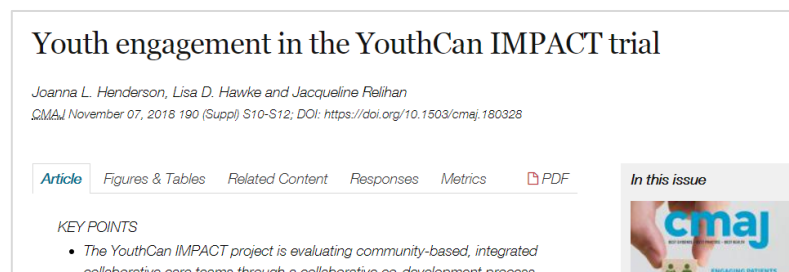
Youth co-developed service postcards



Youth co-authored publications



Henderson, J., Cheung, A., Cleverley, K., Chaim, G., Moretti, M.E., de Oliveira, C., . . . Szatmari, P. (2017). Integrated collaborative care teams to enhance service delivery to youth with mental health and substance use challenges: Protocol for a pragmatic randomised controlled trial. *BMJ Open*, 7(2). © 2017 BMJ Open <https://bmjopen.bmj.com/content/7/2/e014080>; <https://creativecommons.org/licenses/by/4.0/>



Henderson, J.L., Hawke, L.D., & Relihan, J. (2018). Youth engagement in the YouthCan IMPACT trial. *Canadian Medical Association Journal*, 190(Suppl), S10-S12. © 2018 CMAJ. <http://www.cmaj.ca/content/190/supplement/S10>; <https://creativecommons.org/licenses/by-sa/2.5/ca/>

Project summary: Co-production of a web-based drug education resource with and for transitional-aged youth

This project is supported by CAMH Education and the Slaight Family Centre for Youth in Transition.

By using co-production, informed by participatory research methodologies and critical pedagogy to engage transitional-aged youth (TAY), this project aims to co-produce a web-based educational resource with and for TAY that is relevant and effective in supporting them in managing the benefits, risks, and harms related to drugs and drugs use. It started with an exploratory phase to understand drug use and considerations of safety among diverse sets of youth across Ontario. Based on the findings, and working alongside TAY through engagement activities focused on the content, design and purpose of the resource, all stakeholders (group facilitators, study researchers, participants) have the opportunity to contribute to the dialogue on the resource's development.

An ethnographic realist process evaluation is also embedded throughout the project that aims to understand how, for whom, when, and why the co-production of a drug educational resource works.

How have youth been engaged?

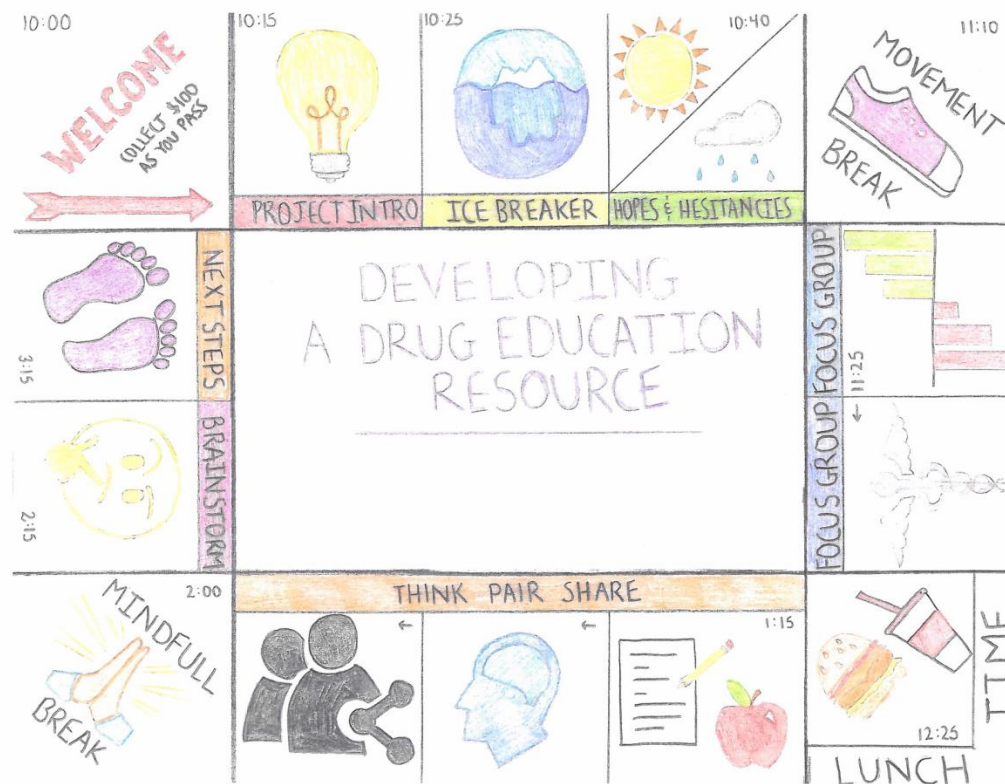
This project was initiated by a team of researchers with the support of youth members during the grant application phase. Youth are currently engaged throughout the project as partners in the exploration, design and development process.

Project activities are co-led by a youth staff and several youth advisors alongside project researchers. A larger youth advisory group meets regularly with the project team to provide guidance and direction for the project. Youth participants in focus groups during the exploration phase of the project also have the opportunity to stay involved in the design and development phase as project advisors. Youth team members are supported by two project allies (a Youth Engagement Coordinator and Project Scientist) and a research analyst.

Key contributions:

- Youth staff advised on youth engagement practices to support the project, including advisor recruitment and onboarding, communications and relationship building strategies.
- Youth staff support for the facilitation of the advisory group.
- Advisors co-designed and co-facilitated five exploratory focus groups. Youth recommended a focus on relationship building activities at the beginning of the groups to support later discussion. This resulted in positive feedback from participants about their experience and interest in continuing with the project.
- Advisors co-designed recruitment materials and resources for focus groups.
- Advisors live across Ontario from communities where the focus groups are held. They supported participant recruitment and used their knowledge and connections in their community to raise awareness and address community specific needs.
- This project is ongoing so new partnership opportunities will emerge through the development phase.

Youth co-developed focus groups



Communications with youth advisory members

Drug-based Education Resource Project Updates



We have completed **5 workshops** in **5 cities** across Ontario (Toronto, London, Hamilton, Ottawa, and Thunder Bay).

A total of **51 young diverse participants** have been recruited.



Area of Living: **69%** Urban; **33%** Suburban; **7%** Rural.



Race/Ethnicity: **39%** White; **33%** Indigenous (First Nations & Métis); **27%** Black; **12%** Asian (South, South East, East); **8%** Mixed Heritage; **6%** Latin American; **2%** Middle Eastern



Gender: **43%** Woman; **33%** Man; **26%** Non-binary; **22%** Trans Man; **2%** Two-Spirit

Sexuality: **59%** Straight/heterosexual; **17%** Queer; **16%** Bisexual; **6%** Gay



Current Student/Employment Status: **47%** Part-time and Self-Employment; **37%** Student; **22%** Unemployed; **9%** Full-time Employment

We would like to **thank you**, all **11** advisory members for your continued participation and feedback on how to collaborate better. We are making changes in how we communicate with you.

While we summarize what we learned, we will invite you to our next advisory meeting in March. A doodle poll will follow.

camh

Project summary: Scoping review of youth friendliness

Studies suggest that to improve utilization of mental health and substance use services by youth, the services should be youth friendly. While youth-serving agencies often define themselves as “youth-friendly,” it was not clear what this term meant. Our team therefore conducted a scoping review of the literature. The project was researcher-initiated and supported by youth team members.

How did we engage youth in the scoping review process?

- Met with youth on staff during project planning to discuss the idea, explain the scoping review methodology, and ensure that the research question was appropriate to the youth experience.
- Discussed possible search terms with the youth team members and made adjustments.
- Discussed preliminary findings with the youth, using their feedback to refine the review.
- Held a member-checking focus group with youth to discuss preliminary results. The focus group was led by a youth on staff, with the researcher present as a co-facilitator. Worked with the youth to develop the focus group questions and process.
- Integrated focus group results into the manuscript.
- Shared the semi-final manuscript with the youth on staff, discussed the findings with them, and made final adjustments to ensure the focus group results were accurately represented and all key youth concerns were addressed in the manuscript.

The project resulted in two manuscripts: A protocol in which the youth are acknowledged, but not co-authors (less contribution) and a final manuscript in which the youth staff member is a co-author*.

*Final manuscript in press: Hawke, L.D., Mehra, K., Settapani, C., Relihan, J. Darnay, K., Chaim, G., Henderson, J. (in press) What makes mental health and addictions services youth friendly? A scoping review of literature. *BMC Health Services Research*



Hawke, L.D., Cleverley, K., Settapani, C., Rice, M., & Henderson, J. (2017). Youth friendliness in mental health and addiction services: Protocol for a scoping review. *BMJ Open*, 7(9), e017555. © 2017 BMJ Open
<https://bmjopen.bmj.com/content/7/9/e017555>; <https://creativecommons.org/licenses/by/4.0/>



PART 7

Youth engagement planning worksheets



Your research project

ENGAGEMENT PLANNING WORKSHEET



What youth-relevant issue will your project be investigating?

What is your study design?

What is your research objective?

What are your anticipated outputs or deliverables?

What are the challenges and barriers to conducting this type of research effectively?

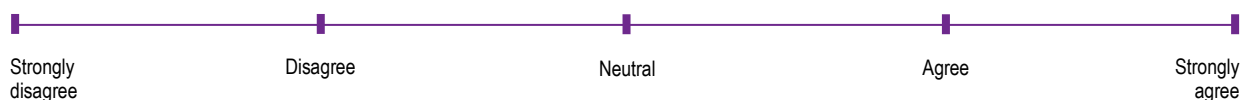
Readiness to engage youth

ENGAGEMENT PLANNING WORKSHEET

The readiness for change model can be helpful to understand what stage you and researchers you work with may be at in engaging youth and to plan for next steps to support engagement in your work. Using the scales below, use a "✓" to indicate where you currently stand in your readiness to engage youth. Use an "x" to indicate where you think your research team stands.

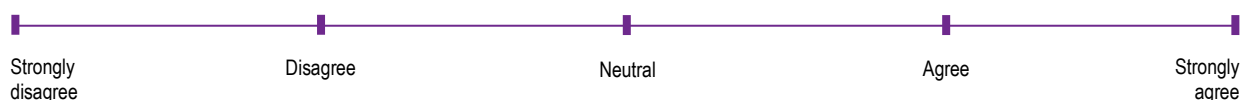
Precontemplation

Researchers in this stage are not thinking seriously about incorporating youth engagement into their work. They may not understand how youth engagement applies to their work or think that the costs outweigh the benefits. They partner with others who have academic expertise, but are not interested in partnering with youth who have lived expertise.



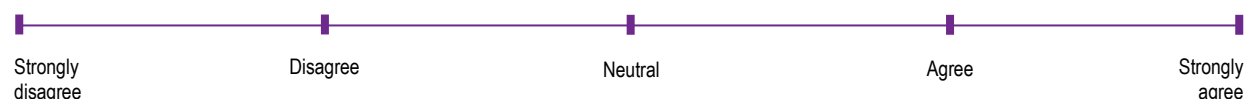
Contemplation

Researchers are considering engaging youth, but have not committed to taking the next step. They may start to understand how a lack of engagement is impacting their work, but generally believe in continuing to work the way they currently do.



Preparation

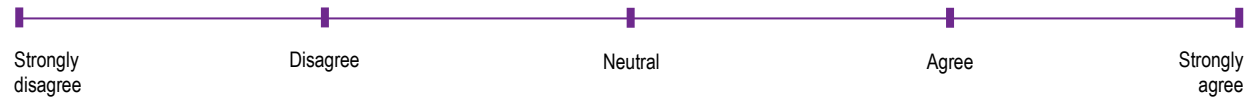
Researchers have taken a recent step to try to incorporate youth engagement into their work. They believe that youth engagement is important and are feeling more committed to making this a part of their work and changing the way that they are doing research.





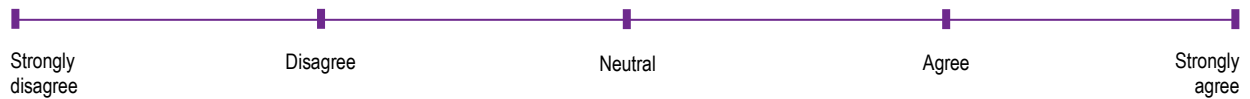
Action

Researchers are taking steps to engage youth in their research. They may be trying different types of engagement techniques and are learning how this can be incorporated into their work.



Maintenance

Researchers have engaged youth and have knowledge of different ways that youth can be engaged in different activities. Researchers have experienced the successes and challenges associated with engagement and are learning from previous projects to plan for continued engagement.



Prochaska, J. O., & DiClemente, C. C. (1982). Transtheoretical therapy: toward a more integrative model of change. *Psychotherapy: theory, research & practice*, 19(3), 276.



Setting the stage for youth engagement

ENGAGEMENT PLANNING WORKSHEET



Project stage

What stage are you currently at in the project?

Have any youth been engaged in your project so far? In what capacity?

Where does your team sit on the Readiness to Change scale? *See previous worksheet..* How could you move up the scale?

What contributions might youth be able to make to your project?



Supporting youth

ENGAGEMENT PLANNING WORKSHEET



Who will be providing mentorship for youth in the role of a project ally?

What training needs will the project ally have? Where is this training available?

What training needs will your research staff have? Where is this training available?

How will you create a *youth-friendly environment*?



Creating youth roles

ENGAGEMENT PLANNING WORKSHEET



Who are the youth that this project addresses? *Think about the specific age range, type of experience, sociodemographic characteristics, etc. that you are focusing on.*

What will the time commitment be for the role for a young person? *Will they need to have flexibility with their schedule? Will there be regular project hours?*

How many youth roles will be available? Will there be youth staff roles and/or youth advisory group roles?

What skills will be required for each of the youth roles on your team? *What skills are needed for a youth team member who has a higher level of responsibility compared to a youth who participates in less frequent advisory meetings?*

**When considering the role for youth on your team, be sure to collaborate with your youth team to develop a joint vision for their role on the project.*



Finding youth to join your team

ENGAGEMENT PLANNING WORKSHEET



How will you recruit youth with the personal characteristics and skill sets you are looking for? Will you create a formal posting or an informal recruitment poster?

What will be included in the recruitment postings or posters? Be as specific and clear as possible about roles, responsibilities, and expectations.

Where will you distribute the recruitment postings and posters? Who will you ask for referrals? Consider agencies that are already working with this youth population, as well as spaces in the community where this youth population can be found.

What will the selection process look like? Who will be involved?



Budgeting for youth engagement

ENGAGEMENT PLANNING WORKSHEET



Youth as project staff or advisors

How many hours do you expect youth to work per week/month? What will their hourly wage be?

What are their training needs and how many hours will that commitment take?

Will you need to hire a staff member to support youth on the project? If so, how many hours do you expect them to work per week/per month and what is their hourly wage? If not, how will the youth be supported?

Youth advisory group

How frequent and how long will your advisory meetings be? How many youth do you expect to attend?

How much will participant honorarium be? How will you provide the honorarium? Cash, gift card, other?



Will you cover travel costs for youth to attend meetings? How and to what extent?

What meeting supplies will be needed? (e.g. fidgets, flip chart, sticky notes, refreshments) How much will you spend?

How many hours of project ally support will you need to coordinate youth engagement activities? What is their hourly wage? Is this a new hire or in-kind hours from an existing team member?

Additional expenses

Will you incur additional printing expenses for youth-friendly flyers and other materials?

Will you have to purchase additional technology (e.g. laptop, software)?



Knowledge translation

Will you produce any resources for the project with youth on your team?

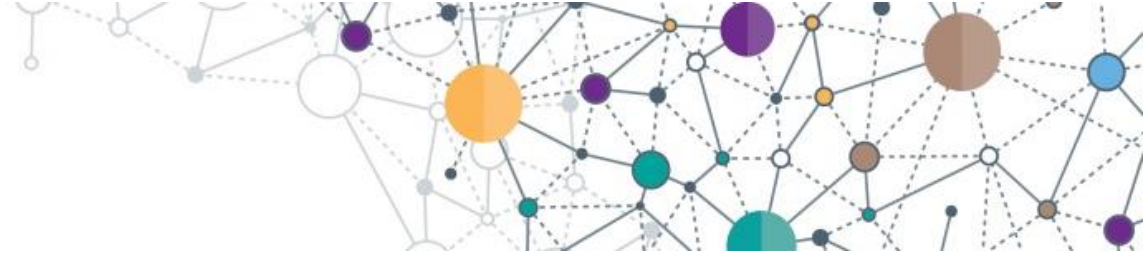
Will youth co-present at any conferences and events? How will they be supported to do so?

What is the time commitment of youth for these contributions?

Finding funding

What grant calls can you integrate engagement expenses into?

What other funding sources might be available? Consider philanthropic sources, partnerships, institutional supports, etc.



What costs might be leveraged through existing resources or in-kind contributions?

BUDGET LINE	HOURS	# OF YOUTH	COST



Learning plan

ENGAGEMENT PLANNING WORKSHEET



This worksheet is designed to be worked through with the youth who have joined your team.

The purpose of this worksheet is for our team to get to know you! It is helpful for us to understand what skills you currently have and any skills you're interested in building as a team member. This way we can work with you in the future to support you through any projects that fit well with your own goals.

Why did you join the research project as a youth team member?

What do you hope to get out of being a member of the research team?

What skills are you bringing to the project?

Are there any skills you are interested in learning or improving upon through the project?



Are there any skills and/or topics that you would be interested in learning more about? (e.g., policy work, research practices, advocacy, meeting facilitation, etc.)

Is there anything we should know about your schedule during the week? (Are you in school, working, etc.)?

Is there any other information about you that project team members should be aware of?



Challenges and possible solutions

ENGAGEMENT PLANNING WORKSHEET



Consider keeping track of the challenges you encounter in the youth engagement process, as well as the solutions you identify to mitigate these challenges.

CHALLENGE	POSSIBLE SOLUTION



Tracking youth contributions

ENGAGEMENT PLANNING WORKSHEET



As you engage youth in research, it is important to keep track of the ways they influence the project. This will help not only for reporting, but for reflecting back on the engagement process and gaining buy-in for future projects.

What changes have been made to the project based on youth feedback? What is the impact?

PROJECT PHASE	CHANGE MADE/IMPACT



PART 8

References and resources

References and resources

About engagement

- Domecq, J. P., Prutsky, G., Elraiyah, T., Wang, Z., Nabhan, M., Shippee, N., ... & Erwin, P. (2014). Patient engagement in research: A systematic review. *BMC Health Services Research*, 14(1), 89. doi:10.1186/1472-6963-14-89
- Faithfull, S., Brophy, L., Pennell, K., & Simmons, M. (2018). Barriers and enablers to meaningful youth participation in mental health research: Qualitative interviews with youth mental health researchers. *Journal of Mental Health*, 28(1), 56-63, doi:10.1080/09638237.2018.1521926
- Heffernan, O. S., Herzog, T. M., Schiralli, J. E., Hawke, L. D., Chaim, G., & Henderson, J. L. (2017). Implementation of a youth-adult partnership model in youth mental health systems research: Challenges and successes. *Health Expectations*, 20(6), 1183-1188. doi:10.1111/hex.12554
- O'Mara-Eves, A., Brunton, G., Oliver, S., Kavanagh, J., Jamal, F., & Thomas, J. (2015). The effectiveness of community engagement in public health interventions for disadvantaged groups: A meta-analysis. *BMC Public Health*, 15(1), 129. doi:10.1186/s12889-015-1352-y
- Wong, N. T., Zimmerman, M. A., & Parker, E. A. (2010). A typology of youth participation and empowerment for child and adolescent health promotion. *American Journal of Community Psychology*, 46(1-2), 100-114. doi:10.1007/s10464-010-9330-0

Practical engagement resources

- Community Mental Health Drug and Alcohol Research Network (CMHDARN). Ask the Experts: A CMHDARN Best Practice Guide to Enabling Consumer and Carer Leadership in Research and Evaluation, Sydney, 2015.
- Hawke, L. D., Relihan, J., Miller, J., McCann, E., Rong, J., Darnay, K., ... & Henderson, J. L. (2018). Engaging youth in research planning, design and execution: Practical recommendations for researchers. *Health Expectations*, 21(6), 944-994. doi:10.1111/hex.12795
- Mizrahi, R., Costa, A., & Youth Advisory Board of the Transitions ACR. (2018). *Tips and Tricks to Starting a Young Adult Council Part 1: 10 Steps to Starting a Young Adult Advisory Council*. Worcester, MA: University of Massachusetts Medical School, Department of Psychiatry, Systems and Psychosocial Advances Research Center (SPARC), Transitions to Adulthood Center for Research.
- Mizrahi, R., Costa, A., & Youth Advisory Board of the Transitions ACR. (2018). *Tips and Tricks to Starting a Young Adult Council Part 2: The Do's and Don'ts of Young Adult Councils*. Worcester, MA: University of Massachusetts Medical School, Department of Psychiatry, Transitions to Adulthood Center for Research.

PERC Advisory Board (October, 2017). *Building Patient Engagement in Research: A Guide for Research Teams*. A product of the INSPIRE-PHC Patient Engagement Resource Centre (PERC)
<https://www.patientengagement-phcresearch.com/>

Evaluating engagement

Abelson, J., Li, K., Wilson, G., Shields, K., Schneider, C., & Boesveld, S. (2016). Supporting quality public and patient engagement in health system organizations: development and usability testing of the Public and Patient Engagement Evaluation Tool. *Health Expectations*, 19(4): 817-827.
<https://doi.org/10.1111/hex.12378>

Boivin, A., L'Esperance, A., Gauvin, F.P., Dumez, V., Macaulay, A.C., Lehoux, P., & Abelson, J. (2018). Patient and public engagement in research and health system decision making: A systematic review of evaluation tools. *Health Expect*, 21(6), 1075-1084. doi: 10.1111/hex.12804

Hamilton, C.B., Hoens, A.M., McQuitty, S., McKinnon, A.M., English, K., Backman, C.L., . . . Li, L.C. (2018). Development and pre-testing of the patient engagement in research scale (peirs) to assess the quality of engagement from a patient perspective. *PLoS One*, 13(11), e0206588. doi: 10.1371/journal.pone.0206588

Youth co-authored/acknowledged publications

Hawke, L.D., Cleverley, K., Settapani, C., Rice, M., & Henderson, J. (2017). Youth friendliness in mental health and addiction services: Protocol for a scoping review. *BMJ Open*, 7(9), e017555.
doi:10.1136/bmjopen-2017-017555

Hawke, L.D., Mehra, K., Settapani, C., Relihan, J., Darnay, K., Chaim, G., Henderson, J. (in press). What makes mental health and addictions services youth friendly? A scoping review of literature. *BMC Health Services Research*.

Hawke, L. D., Relihan, J., Miller, J., McCann, E., Rong, J., Darnay, K., ... & Henderson, J. L. (2018). Engaging youth in research planning, design and execution: Practical recommendations for researchers. *Health Expectations*, 21(6), 944-994. doi:10.1111/hex.12795

Heffernan, O. S., Herzog, T. M., Schiralli, J. E., Hawke, L. D., Chaim, G., & Henderson, J. L. (2017). Implementation of a youth-adult partnership model in youth mental health systems research: Challenges and successes. *Health Expectations*, 20(6), 1183-1188. doi:10.1111/hex.12554

Henderson, J.L., Cheung, A., Cleverley, K., Chaim, G., Moretti, M.E., de Oliveira, C., Hawke, L.D., Willan, A.R., O'Brien, D., Heffernan, O.*, Herzog, T.*, Courey, L., McDonald, H., Grant, E., Szatmari, P. (2017). Integrated collaborative care teams to enhance service delivery to youth with mental health and substance use challenges: Protocol for a pragmatic randomised controlled trial. *BMJ Open*, 7(2), e014080. doi:10.1136/bmjopen-2016-014080

- Henderson, J.L., Hawke, L.D., & Relihan, J. (2018). Youth engagement in the YouthCan IMPACT trial. *Canadian Medical Association Journal*, 190 (Suppl), S10-S12. doi:10.1503/cmaj.180328
- Kidd, S. A., Vitopoulos, N., Frederick, T., Daley, M., Peters, K., Clarc, K., ... & McKenzie, K. (2019). Peer Support in the Homeless Youth Context: Requirements, Design, and Outcomes. *Child and Adolescent Social Work Journal*, 1-14. doi: 10.1007/s10560-019-00610-1
- Vitopoulos, N. A., Frederick, T. J., Leon, S., Daley, M., McDonald, C., Morales, S., ... & Gutierrez, R. (2018). Development of a complex tertiary prevention intervention for the transition out of youth homelessness. *Children and Youth Services Review*, 94, 579-588. doi: 10.1016/j.childyouth.2018.08.038
- Wisdom2Action. (2018). How are we doing? A participatory evaluation of Youth-Advisory Council engagement at the Wisdom2Action Network. Available at: <https://www.wisdom2action.org/resources/reports/>

Other references

- Bray, J., Liebenberg, L., & Zinck, E. (2014). *Ethics and Research with Young People in Challenging Contexts*. CYCC Network, Halifax, NS. Available at: <http://www.cycnetwork.org/en/pp/cycc-reports>
- Henderson, J.L., Brownlie, E., Rosenkranz, S., Chaim, G., & Beitchman, J. (2013). Integrated knowledge translation and grant development: Addressing the research practice gap through stakeholder-informed research. *Journal of the Canadian Academy of Child and Adolescent Psychiatry*, 22(4), 268–274.
- Prochaska, J. O., & DiClemente, C. C. (1982). Transtheoretical therapy: Toward a more integrative model of change. *Psychotherapy: Theory, Research & Practice*, 19(3), 276. doi:10.1037/h0088437

This image shows a single sheet of white paper with horizontal ruling lines. The lines are evenly spaced and run across the width of the page. There are no margins, text, or other markings on the paper.

Notes

[illegible]

